The Caregiver Guide

Module 15

Caring for a Family Member with Mental Illness

Participant Booklet

UCARE Module 15
Caring for a Family Member with Mental Illness

PURPOSE

Module 15 will provide caregivers of a family member who has mental illness with facts about mental illness. In this module we will discuss symptoms of mental illness, including emotional reactions that are common among family members, and information about local programs that are available to help family members and persons with mental illness.

WHAT YOU WILL LEARN

After completing this module, you will be able to:

1. List basic facts about mental illness and recovery
2. Recognize symptoms of mental illness
3. Identify stages of emotional reactions among family members
4. Express feelings about what it's like to be a spouse, parent, or sibling of someone with serious mental illness
5. Identify community resources that provide support to families and individuals with mental illness
6. Describe a specific action that you will take in the following week to take care of yourself

BASIC FACTS ABOUT MENTAL ILLNESS AND RECOVERY

Facts about mental illness:

- Mental illnesses are biologically based brain disorders. They cannot be overcome through "will power" and are not related to a person's "character" or intelligence
- Mental illnesses strike individuals in the prime of their lives, often during adolescence and young adulthood. All ages are susceptible, but the young and the old are especially vulnerable
- Without treatment the consequences of mental illness for the individual and society are staggering: unnecessary disability, unemployment, substance abuse, homelessness, inappropriate incarceration, suicide and wasted lives
- The economic cost of untreated mental illness is more than 100 billion dollars each year in the United States

Facts about recovery:

- The best treatments for serious mental illnesses today are highly effective
- Yet, treatment is not a “cure” and symptoms can come and go in cycles
- Between 70 and 90 percent of individuals have significant reduction of symptoms and improved quality of life with a combination of medication and psychosocial treatment and supports
- Early identification and treatment is of vital importance
- By getting people the treatment they need early, recovery may be accelerated
- Treatment may protect the brain from further harm related to the course of illness

Notes:

SYMTOMS AND TREATMENT

Treatment for mental illness is usually directed by a diagnosis. Once a person is given a diagnosis, that "label" may guide the type of treatment recommended. This module will not answer any technical questions you may have about your family member's diagnosis or treatment. However, you may want to research on your own what is known about the diagnosis or "label" that has been given to describe your family member's condition. In the Resource section of this Booklet there are brief descriptions of major mental conditions. These one-page descriptions indicate symptoms and the types of treatment usually recommended for each condition. The information was obtained from the National Institute of Mental Health website. Further information can be obtained by visiting the website.

To research symptoms and treatment of mental illness

- National Institute of Mental Health (NIMH) website: www.nimh.nih.gov

Notes:

SYMPTOMS OF MENTAL ILLNESS

These changes are very discomforting.

One of the most difficult things to deal with in regard to the person with mental illness is the change in behavior of your family member. The person may act in ways that you have never seen before and that are confusing. This is not the person you know. The person you know does not act this way. These changes are very discomforting. You don't know how to respond. You miss the person you knew, and could count on him/her to act in certain ways.

The following chart lists behaviors that are symptoms of mental illness. You may recognize these in your family member. Read the left side of the list and check the behaviors that you see in your family member.
Are these new behaviors?

Now read the right side of the list and check the behaviors you used to see but no longer see in your family member. Do you miss the person who did these things?

UNDERSTANDING SYMTOMS OF MENTAL ILLNESS

New behaviors you now see	Behaviors you used to see
Constant tension and nervousness Irritability, often critical, even abusive Unpredictable, over-reaction to things Indifference; inflexible obstinacy Irrational statements and responses Obsession with own activities and pursuits; inflated self concept Forgetfulness and losing things Uncontrollable sadness or crying Rudeness and hostility Fearfulness and hyper-vigilance Devastated by peer disapproval Disinterest in sex or can't get enough Indecisiveness Inappropriate and bizarre behaviors Desire to be withdrawn and isolated	Ability to focus and concentrate Insight about what is happening Pride in appearance and personal hygiene Capacity for intimacy Ability to cope with minor problems Enjoyment of family, friends, work Ability to practice self control Optimism, faith, belief in the future Warmth and thoughtfulness in relationships Ability to appreciate people and accept their help Pride in taking responsibility Ability to express joy Capacity to see another point of view Willingness to follow treatment when ill
Changed due to the illness	Lost due to the illness

STAGES OF EMOTIONAL REACTIONS AMONG FAMILY MEMBERS

The National Alliance on Mental Illness, or NAMI, is a non-profit organization that provides education, support and advocacy for those with mental illness and their family members. NAMI has identified **three** major stages of emotional reactions among family members as they learn to deal with the illness of a person. These are common reactions that people experience as they try to cope. Families often experience a "roller coaster" of emotions and it sometimes is helpful for them to learn that their reactions are typical. They are not alone or unique in their experiences. They have to go through a grieving process with stages that do not start and stop at predictable periods of time. One may experience denial for a long time then move into anger and very quickly into depression. Family members' reactions may cycle around in and out of the various emotions.

These stages that we will describe in this session come from the Family-to-Family class developed by NAMI. Their classes are available statewide.

Stage 1: Usually occurs when your family has to deal with a catastrophic event. A crisis occurs and you don't want to believe it. A crisis might be failure in school, a divorce or domestic violence. You are in shock. You feel overwhelmed and dazed. It's common to feel guilt and shame. But you also want to rationalize what happened, to find an explanation that makes it okay. In this stage you really don't know what to do or where to turn. You want things to

become “normal” again. But you are beginning to recognize that some things have fundamentally changed.

The loss of the family member that you “knew” brings a deep grief.

Stage 2: Learning to cope. Anger, guilt, and resentment are all part of the coping stage. The anger may be directed toward the family member with mental illness and/or it may be directed inward at yourself by constantly feeling guilty about what you should have done differently. Acknowledging your feelings and recognizing that this is an important part of the process is critical. With time, you have recognized the extent of the changes and understand that these changes will affect the future of your family member and you as well. And the loss of the family member that you “knew” brings a deep grief.

Stage 3: Moves from the despair and guilt and grief to an understanding of the challenges your family member is facing and the courage they have to deal with the illness. Acceptance is recognizing that no one is to blame and that you can move forward. It is at this point that you may become an advocate and use your understanding to join others in support and advocacy activities

Notes:

STAGES OF EMOTIONAL REACTIONS IN FAMILY MEMBERS

1. Dealing with the catastrophic event

Crisis and Shock
- Feeling overwhelmed
- In a daze
- We don't know how to deal with it

Denial
- This is not really serious
- There is a perfectly logical explanation for this
- This will pass

Dawning of Recognition
- Hoping that this is not long term
- Somehow everything will magically go back to normal
- Hoping against hope

2. Learning to cope

Anger / Guilt / Resentment
- We start to blame the victim
- Insist that the person "snap out of it"
- Harbor guilt, fearing that it really *is* our fault
- Torment ourselves with self-blame

Recognition
- The fact that mental illness happened to someone we love becomes a reality for us
- We know it will change our lives together

Grief
- We deeply feel a loss of the person we knew
- Our future together is uncertain
- Sadness that does not go away

3. Becoming an advocate

Understanding
- Empathy for what our loved one is suffering
- Respect for the courage it takes to cope with the illness

Acceptance
- It's nobody's fault
- It's a sad and difficult life experience, but we will hang in there

Advocacy / action
- Focus your anger and grief to advocate for others
- Join public advocacy groups and become involved

HELEN'S STORY

As you read this story identify the stages from page 8.

Helen was a graduate student and teaching assistant at a local university. She had a second part time job off-campus at a research laboratory. She worked and studied 60-70 hours per week and went out on weekends to local clubs with her friends. Her parents were worried that she would "burn out" with working so many hours and hard partying. But they rationalized that Helen was young and she seemed to be handling everything okay. Besides, Helen was an adult and they didn't want to appear as if they were treating her like an adolescent.

As a teaching assistant, Helen was supposed to grade mid-term exams for the Biology class. Her professor continually asked her when they would be graded, but Helen kept making excuses. Finally, by the end of the semester Helen had not graded any mid-term exams and the professor had to ask another teaching assistant to grade the exams in time to submit the grades. Helen apologized to the professor and explained that her off-campus job had been very demanding and she was carrying a heavy school load this semester. She also apologized to the teaching assistant by taking him out to dinner because he had to do her work for her (grade the exams).

The Biology professor considered firing Helen from her job as a teaching assistant before the next school year. He was reluctant because he knew she was smart and hard working, and he did not want her to drop out of school. In the end, she was allowed to keep her job for the next school year.

At the beginning of her second year as a teaching assistant, Helen was assigned to a new professor. Because this professor had been warned that Helen tended to procrastinate, he set up a strict schedule for her grading to be completed. Helen agreed to and signed this schedule because she wanted to perform well after last year's embarrassment. Despite all of Helen's promises and the strict expectations of the new professor, the same thing happened and the exams did not get graded by the end of the semester. The professor tried to contact Helen at school and at home to get the exams back, but was unsuccessful. Finally he called her parents in another town to see if they knew where she was. Helen's parents drove to her apartment where they found Helen hiding under her bedcovers. She had been in her apartment for a week – not eating or talking to anyone. They found the ungraded exams on her dining room table.

Helen was admitted to an inpatient psychiatric unit to treat her depression. She was eventually diagnosed with bi-polar disorder.

Notes:

COMMUNITY RESOURCES

There are some very good community resources that can help your family to find the information you need. NAMI has a Family-to-Family education program that is a free 12 week course. In addition NAMI has a course called "B.R.I.D.G.E.S." for the person with mental illness. The organization has support groups as well as mentors for family members and mentors for consumers. Staff and volunteers can provide the appropriate support and help that is needed.

Some programs that are offered by NAMI are:

Family-to-Family Education Program – A free 12-week course for families of people who have mental illnesses. Family members can unite together to support each other and receive valuable education about signs and symptoms of mental illness, medications, emotional stages, effective coping skills, problem solving and communication. Classes also offered in Spanish.

B.R.I.D.G.E.S. (Building Recovery of Individual Dreams and Goals through Education and Support) -- A free 10-week course for consumers of mental health services and those interested in establishing and maintaining their wellness and recovery.

Mentoring Program provides a personal coach who can empower consumers to reach for more independence and raise their self esteem. The mentors provide guidance in finding support groups, setting realistic goals, moving back into society, and staying out of the hospital.

Hope for Tomorrow is a Mental Health Education Program offered for middle schools and high schools. It brings together the combined efforts and insights of mental health professionals, educators, and other experts to help parents, teachers, students and communities to understand mental illness – a crucial step to improving the lives of those affected by it.

Support Groups are available across the state for family members, friends and consumers looking for the support from those who understand.

Clergy Training and Provider Training provides training to clergy members and general health and mental health providers. Each training is taught by a panel of family members, consumers, and professionals. Participants receive training on mental illness, ways to offer support to both the consumers and the families, and resources available in the community.

For more information and class sign-up, contact

NAMI Utah
450 S 900 E #160
Salt Lake City, UT 84102
(801) 323-9900 Toll free: 1-877-230-6264
Website: www.namiut.org
Email: education@namiut.org

TAKE CARE OF YOURSELF

Taking care of yourself is often overlooked. The needs of other family members are often neglected. Families need reassurance, hope and to learn how best to deal with a loved one.

What advice would you give to someone in a similar position to you (as a spouse, parent, sibling) of a person with mental illness?

What do you do to take care of yourself? Write down one thing you will do FOR YOURSELF this week.

This week I commit to doing for myself:

I will accomplish this by _____ (date)
I will tell _____(person)
that I have done something for myself this week.

RESOURCES

SYMPTOMS AND TREATMENT FOR MAJOR MENTAL ILLNESS

ANXIETY DISORDERS

What are Anxiety Disorders?

Anxiety is a normal reaction to stress. It helps one deal with a tense situation in the office, study harder for an exam, keep focused on an important speech. In general, it helps one cope. But when anxiety becomes an excessive, irrational dread of everyday situations, it has become a disabling disorder.

Five major types of anxiety disorders are:

- Generalized Anxiety Disorder
- Obsessive-Compulsive Disorder (OCD)
- Panic Disorder
- Post-Traumatic Stress Disorder (PTSD)
- Social Phobia (or Social Anxiety Disorder)

Treatment:

Effective treatments for anxiety disorders are available, and research is yielding new, improved therapies that can help most people with anxiety disorders lead productive, fulfilling lives.

A detailed booklet that describes Anxiety Disorders, the symptoms, causes and treatments of the major anxiety disorders, with information on getting help and coping (2000 [rev], cited Feb 2006) can be found at:

http://www.nimh.nih.gov/publicat/NIMHanxiety.pdf

ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)

What is Attention Deficit Hyperactivity Disorder?

Attention Deficit Hyperactivity Disorder, ADHD, is one of the most common mental disorders that develop in children. Children with ADHD have impaired functioning in multiple settings, including home, school, and in relationships with peers. If untreated, the disorder can have long-term adverse effects into adolescence and adulthood.

Signs and Symptoms:

Symptoms of ADHD will appear over the course of many months, and include:

- Impulsiveness: a child who acts quickly without thinking first
- Hyperactivity: a child who can't sit still, walks, runs, or climbs around when others are seated, talks when others are talking
- Inattention: a child who daydreams or seems to be in another world, is sidetracked by what is going on around him or her

How is it diagnosed?

If ADHD is suspected, the diagnosis should be made by a professional with training in ADHD. This includes child psychiatrists, psychologists, developmental/behavioral pediatricians, behavioral neurologists, and clinical social workers. After ruling out other possible reasons for the child's behavior, the specialist checks the child's school and medical records and talks to teachers and parents who have filled out a behavior rating scale for the child. A diagnosis is made only after all this information has been considered.

Treatment:

Effective treatments for ADHD are available, and include behavioral therapy and medications.

A detailed booklet that describes ADHD, the symptoms, causes, and treatments, with information on getting help and coping (2003 [rev], cited Feb 2006) can be found at: www.nimh.nih.gov/publicat/NIMHadhdpub.pdf

AUTISM SPECTRUM DISORDERS (PERVASIVE DEVELOPMENTAL DISORDERS)

What are Autism Spectrum Disorders?

Autism Spectrum Disorders (ASD), also known as Pervasive Developmental Disorders (PDDs), cause severe and pervasive impairment in thinking, feeling, language, and the ability to relate to others. These disorders are usually first diagnosed in early childhood and range from a severe form, called autistic disorder, through pervasive development disorder not otherwise specified (PDD-NOS), to a much milder form, Asperger syndrome. They also include two rare disorders, Rett syndrome and childhood disintegrative disorder.

Signs and Symptoms:

Parents are usually the first to notice unusual behaviors in their child. In some cases, the baby seemed "different" from birth, unresponsive to people or focusing intently on one item for long periods of time. The first signs of an autism spectrum disorder can also appear in children who had been developing normally. When an affectionate, babbling toddler suddenly becomes silent, withdrawn, self-abusive, or indifferent to social overtures, something is wrong.

Treatment:

There is no single best treatment package for all children with ASD. Decisions about the best treatment, or combination of treatments, should be made by the parents with the assistance of a trusted expert diagnostic team.

A detailed booklet that describes Autism Spectrum Disorders, the symptoms, causes, and treatments, with information on getting help and coping (2004, cited Feb 2006) can be found at: www.nimh.nih.gov/publicat/autism.cfm

BIPOLAR DISORDER

What is Bipolar Disorder?

Bipolar Disorder, also known as manic-depressive illness, is a serious medical illness that causes shifts in a person's mood, energy, and ability to function. Different from the normal ups and downs that everyone goes through, the symptoms of bipolar disorder are severe.

Signs and Symptoms:

Bipolar disorder causes dramatic mood swings from overly "high" and/or irritable to sad and hopeless, and then back again, often with periods of normal mood in between. Severe changes in energy and behavior go along with these changes in mood. The periods of highs and lows are called episodes of mania and depression.

Treatment:

Most people with bipolar disorder can achieve substantial stabilization of their mood swings and related symptoms over time with proper treatment. A strategy that combines medication and psychosocial treatment is optimal for managing the disorder over time.

A detailed booklet that describes symptoms, causes, and treatments, with information on getting help and coping (2001, cited Feb 2006) can be found at www.nimh.nih.gov/publicat/NIMHbipolar.pdf

BORDERLINE PERSONALITY DISORDER

What is Borderline Personality Disorder?

Borderline personality disorder (BPD) is a serious mental illness characterized by pervasive instability in moods, interpersonal relationships, self-image, and behavior. This instability often disrupts family and work life, long-term planning, and the individual's sense of self-identity.

Signs and Symptoms:

While a person with depression or bipolar disorder typically endures the same mood for weeks, a person with BPD may experience intense bouts of anger, depression, and anxiety that may last only hours, or at most a day.[5] These may be associated with episodes of impulsive aggression, self-injury, and drug or alcohol abuse. Distortions in cognition and sense of self can lead to frequent changes in long-term goals, career plans, jobs, friendships, gender identity, and values.

Treatment:

Treatments for BPD have improved in recent years. Group and individual psychotherapy are at least partially effective for many patients.

A brief overview that focuses on Borderline Personality Disorder, the symptoms, treatments, and research findings (2001, cited Feb 2006) can be found at: www.nimh.nih.gov/publicat/NIMHbpd.pdf

DEPRESSION

What is Depression?

Depression is a serious medical illness; it's not something that you have made up in your head. It's more than just feeling "down in the dumps" or "blue" for a few days. It's feeling "down" and "low" and "hopeless" for weeks at a time.

Signs and Symptoms:

- Persistent sad, anxious, or "empty" mood
- Feelings of hopelessness, pessimism
- Feelings of guilt, worthlessness, helplessness
- Loss of interest or pleasure in hobbies and activities that were once enjoyed

Treatment:

A variety of treatments including medications and short-term psychotherapies have proven effective for depression.

A detailed booklet that describes depression, the symptoms, causes, and treatments, with information on getting help and coping (Date: 2000, cited Feb 2006) can be found at: www.nimh.nih.gov/publicat/nimhdepression.pdf

EATING DISORDERS

What are Eating Disorders?

Eating disorders are not due to a failure of will or behavior; rather, they are real, treatable medical illnesses in which certain maladaptive patterns of eating take on a life of their own. The main types of eating disorders are anorexia nervosa and bulimia nervosa.

Eating disorders frequently co-occur with other psychiatric disorders such as depression, substance abuse, and anxiety disorders.[1] In addition, people who suffer from eating disorders can experience a wide range of physical health complications, including serious heart conditions and kidney failure which may lead to death. Recognition of eating disorders as real and treatable diseases, therefore, is critically important.

Signs and Symptoms

Symptoms of anorexia nervosa include:

- Resistance to maintaining body weight at or above a minimally normal weight for age and height
- Intense fear of gaining weight or becoming fat, even though underweight

Symptoms of bulimia nervosa include:

- Recurrent episodes of binge eating, characterized by eating an excessive amount of food within a discrete period of time and by a sense of lack of control over eating during the episode

- Recurrent inappropriate compensatory behavior in order to prevent weight gain, such as self-induced vomiting or misuse of laxatives, diuretics, enemas, or other medications (purging), fasting, or excessive exercise

Treatment

Eating disorders can be treated and a healthy weight restored. The sooner these disorders are diagnosed and treated, the better the outcomes are likely to be. Because of their complexity, eating disorders require a comprehensive treatment plan involving medical care and monitoring, psychosocial interventions, nutritional counseling and, when appropriate, medication management.

Treatment of anorexia calls for a specific program that involves three main phases: (1) restoring weight lost to severe dieting and purging; (2) treating psychological disturbances such as distortion of body image, low self-esteem, and interpersonal conflicts; and (3) achieving long-term remission and rehabilitation, or full recovery.

A detailed booklet that describes Eating Disorders, the symptoms, causes, and treatments, with information on getting help and coping (2001, cited February 2006) can be found at: www.nimh.nih.gov/publicat/NIMHeatingdisorder.pdf

SCHIZOPHRENIA

What is Schizophrenia?

Schizophrenia is a chronic, severe, and disabling brain disorder that affects about 1 percent of people all over the world. People with schizophrenia sometimes hear voices others don't hear, believe that others are broadcasting their thoughts to the world, or become convinced that others are plotting to harm them. These experiences can make them fearful and withdrawn and cause difficulties when they try to have relationships with others.

Signs and Symptoms:

Symptoms usually develop in men in their late teens or early twenties and women in the twenties and thirties, but in rare cases, can appear in childhood. They can include hallucinations, delusions, disordered thinking, movement disorders, flat affect, social withdrawal, and cognitive deficits.

Treatment:

This is a time of hope for people with schizophrenia. Although the causes of the disease have not yet been determined, current treatments can eliminate many of the symptoms and allow people with schizophrenia to live independent and fulfilling lives in the community.

A detailed booklet that describes schizophrenia, the symptoms, causes, and treatments, with information on getting help and coping (Date: 2005 [rev]; cited Feb 2006) can be found at www.nimh.nih.gov/publicat/schizoph.cfm#readNow

ORGANIZATIONS

NAMI Utah is a non-profit organization that provides education, support and advocacy for those with mental illness and their family members.
http://www.namiut.org
450 South 900 East
Salt Lake City, UT 84102
Voice/TTY (801) 323-9900 Fax: (801) 323-9799
Toll Free: 1-877-230-6264
Email: Chandra@namiut.org

National Alliance for Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to improving the lives of persons living with serious mental illness and their families. Founded in 1979, NAMI has become the nation's voice on mental illness, a national organization including NAMI organizations in every state and in over 1100 local communities across the country who join together to meet the NAMI mission through advocacy, research, support, and education. www.nami.org Toll free HelpLine: 1-888-999-6264.

National Institute of Mental Health (NIMH) National Institute of Mental Health, National Institutes of Health, US Department of Health and Human Services, work to improve mental health through biomedical research on mind, brain, and behavior. www.nimh.nih.gov